

## Executive Summary

The national agenda for children and adolescents with special health care needs is committed to improving services, preparing and training health care workers in the field, and encouraging appropriate research. This agenda includes the issue of young people moving from pediatric services to adult health care. This period of transition can be an anxiety provoking time for adolescents, their families, and for those who work on their behalf, and further efforts must be made to bridge this potential gap in services.

In order to address this important health care concern, the Surgeon General convened a small invitational conference "Growing Up and Getting Medical Care: Youth with Special Health Care Needs" on March 13-15, 1989 at the Jekyll Island Club, Jekyll Island, Georgia. The ground work for this meeting had been laid at a previous conference: "Youth with Disability: The Transition Years," which was held in Minnesota in 1984. The focus of this earlier meeting was mainly to define the problem in broad terms and to identify the challenges for adolescents with special needs as they move onto the adult service system. At Jekyll Island, the Surgeon General hoped to see the development of specific strategies and action steps related to medical care.

It is agreed that during this period of transition, there is likely to be a hiatus in the provision and utilization of appropriate care. The young adult, the family, and health care providers are all affected by this change.

- The young adult himself may have had little warning or preparation for leaving the familiar health environment he has grown to trust and depend upon, and now he must find his way to a new clinical setting where he is expected to behave independently and where the personal touch may appear to be missing. Even when there is intellectual recognition that an adult patient's role is now more appropriate when receiving health care, it is often hard to move ahead in a positive frame of mind.
- Parents and other family members may feel threatened by approaching changes in the pattern of care, and resent the effort required to adjust to a new setting and different staff. They have weathered many crises and vital decision making with the support of the Pediatric team, and have come to regard this strong source of advocacy as a permanent arrangement. In contrast, they may perceive the internist as less involved and perhaps insensitive to the subtleties associated with these chronic medical conditions.
- Health care providers also may feel uncomfortable during the period of change. The pediatrician has seen the survival of the child with a handicap which has been a professional and personal achievement; it is therefore frustrating to relinquish such a patient to others who provide a service which may have a somewhat different focus and broader goals. The internist accepts the patient who has already been diagnosed and treated. Whatever he says or does will inevitably be compared with what has previously transpired in the child centered setting. As a rule, he does not have the back up of an interdisciplinary team. The medical condition may be one with which he has had little or no experience. To build a productive relationship under these circumstances could seem an unreasonable challenge. The care of adults in many settings tends to focus on the medical problem; whereas, pediatricians have learned to attempt a more holistic approach.

Issues in transition that must be addressed include the provision of services, financing of care, training of staff, and research.

- Provision of services - various methods have been tried to assure a smooth transition; these models appear to have been successful, and point the way to building on existing resources in any given situation.
- Financing of care - having determined that responsive health services are available, the most pressing issue in transition must be the financial capability to pay for this care. The young person who reaches the age of legal independence, but

has a pre-existing condition, may find he is virtually uninsurable. Whether he is in full time education, employed, or at home, the procurement of adequate financial coverage is a major barrier to obtaining comprehensive health care.

- Training of staff - those responsible before, during, and after transition need an orientation to the developmental characteristics of young people who are attempting to make this adjustment. Knowledge of some of the less common medical conditions should be made more available. The importance of a positive relationship between patients, their families, and care providers must be stressed. Understanding and assessment of the emotional, economic, and social needs of families should be developed in tandem with the monitoring of the long term medical condition.
- Research - there is a lack of precise information about landmarks in development which have a bearing upon the optimal timing for transition. The significance of the impact of various chronic medical conditions upon psychosocial development is unclear. Demographic data have been collected, but analysis which would give the information practical value has yet to be performed.

As a result of this conference, a number of action steps will be planned and implemented.

- Conference participants will make their respective professional groups more aware of the importance of transition. This will be achieved through contact with professional organizations, newsletters, and presentation of papers.
- Support groups who are already known to many families will be encouraged to work with official agencies on the health aspects of transition.
- Generic guidelines will be developed which will recommend the scope for both individual and programmatic components of health care. These guidelines should provide a basis for assessment of an individual's readiness for transfer. Available options for the financing of needed services are to be a major inclusion.
- A financing coalition will be developed with representatives from several national agencies and organizations. These experts will be selected because of their interest and experience with the predicament with which disabled adolescents are frequently faced. The group will concentrate upon exploring funding initiatives for transition and beyond, in keeping with emerging fiscal structures. Access to financial support and a standard benefit design will be pivotal points in these deliberations.
- Strengthening of family empowerment teaching resources will be made available through support groups, voluntary organizations, and official agencies.
- Training efforts will be encouraged to broaden the horizon of staff in both pediatric and adult settings about the significance of transition and health care beyond this point.
- Universities will be encouraged to analyze existing data relative to transition issues. Information will be sought about the measurement of functional disabilities, the definition of disability in a socio-economic context, the effect of a disability on development, and other topics related to transition.

An adolescent may have any one of a great number of primary disabling conditions; however, there are wide areas of common needs which are shared by all regardless of the nature of their illness. These shared needs often relate to developmental delays which require special support at the time of transition, and about which too little is known.

The recognition of common needs has implications for staffing patterns, especially for those who provide counseling for psychosocial and family issues. The whole community of professionals must become increasingly aware that they may need to modify their attitudes around the process of transition, and build new skills into their repertoire in order to respond to both individuals and categorical groups of patients.

**Introductory Remarks**  
**by**  
**C. Everett Koop, M.D.**  
**Surgeon General**  
**U.S. Public Health Service**  
**Department of Health and Human Services**

As I end my career as Surgeon General and look back on my accomplishments, I share with you an enormous sense of satisfaction in what we have achieved for children with special health care needs and their families.

We have established a national agenda for these children and their families which is to:

- Pledge a national commitment to all children with special health care needs and their families.
- Encourage building community-based service systems.
- Assist in ensuring adequate preparation of the professionals who provide care.
- Develop coalitions to improve the delivery of services.
- Establish guidelines to control costs of services.
- Encourage and support the development of adequate health care financing.
- Continue to conduct research and disseminate information.

This agenda is moving forward as evidenced by the more than 1,200 participants from medicine, health, education, social service fields, and families who joined us at the September 1988 Surgeon General's Conference in Washington, D.C. to share the progress we had made.

Before I leave my position, I would like to recall one major issue in the care of special children which has not been adequately addressed and which is a significant barrier to our adolescent and young adult population as they pursue independence. I refer to the obstacles they encounter and must surmount if the provision and quality of medical care is to continue from childhood through transition to adulthood.

I have invited you as leaders in the major organizations and professions which provide these services to help us solve that problem.

This Surgeon General's Workshop, which will probably be my last, is a personal effort to close the loop on the conference some of us had in June, 1984 at Wayzata, Minnesota -- A "Conference on Youth With Disabilities: The Transition Years." There, I was a speaker who asked "who are the disabled among us." I left the question unanswered but implied that some members of society were more handicapped than those we call disabled -- handicapped by attitude, prejudice and tunnel vision.

Today, I am your keynote speaker and in a sense, your host. It is necessary and potentially profitable, to hold this workshop to determine methods for improving the transition of disabled youngsters from Pediatric care to physicians in Adult Medicine and associated specialties.

What has been achieved already?

- There are programs that work and about them you will hear more.
- The issue of transition is being addressed by a number of regional and national programs, models, and networking services which will teach us how better to encourage adolescents to develop their full potential.
- There are societies and associations that foster the exchange of information among those of like mind, such as the Society for Adolescent Medicine.
- There are some states that have coordinators for adolescent health programs.
- And some states have training and employment models.

What is wrong with available transition services and concepts?

- Some physicians for adults and their associates have not yet acquired the medical expertise for working effectively with rare medical conditions which

- can affect the young adult population.
- Pediatric professionals may have become overprotective of their patients which tends to inhibit the development of independence for the patient.
- The patient may receive a negative message of survival if he stays in pediatrics indefinitely.

I personally spent much of my professional life making sure that children with surgical problems continued to receive good comprehensive care in an adult world. We know that some physicians for adults and their associates have limited experience in caring for older children and adolescents and they must be given every opportunity to fill this gap in knowledge and skills.

We are not asking you to consider a series of problems with easy solutions. Our concerns are not amenable to a quick fix.

A basic underlying defect in the system has to do with the lack of a transition protocol for healthy adolescents from pediatric care to adult services. Part of that is because the population in general has its healthiest years in the decade after adolescence. Even individuals under the care of a family practitioner have little reason to seek his help and when an acute illness requires medical attention, it is likely that consultation will be with a different and unknown physician. How much more difficult for the youngsters with special needs when his/her acute illness demands entry to the adult system.

Some of the barriers to a successful transition of children with special health care needs have already been identified. Attitudinal barriers come first and they involve patients, parents, the pediatric caregivers and their adult counterparts. The pediatricians and internists in this audience have given much thought to these issues and therefore probably do not represent the profession as a whole.

Adolescents are having more trouble than they need with this aspect of growing up; however, they themselves do not lack enthusiasm to become involved in transition and can see future benefits in moving on to a state of greater autonomy.

Parents are understandably unwilling to leave the familiarity, security and expertise of child centered services and to enter an unknown territory, which usually seems to compare unfavorably with the known, at least in the initial phases.

Pediatricians and their associates, having a tremendous interest and investment in the recipients of their care, feel a proprietary responsibility that encourages them to cling to the patient even when they know it is in the patient's best interests to make a change. Sometimes it may seem that the immediate adult care is not entirely responsive.

The new responsible adult care giver has many hurdles to surmount. First, the idea that pediatricians play medical games with their patients and over-indulge their patient's parents; second, the fact that the parents know more than he/she does about the child, his problem, and the goals for his care; third, the idea that it is normal for parents to be anxious, to expect satisfactory explanations, and to wish for inclusion when decisions are made, which all takes valuable professional time.

The adult care giver will probably never have the same creative interest that was the vital ingredient of the former relationship, indeed it may have been the adhesive that held the situation together.

Some diagnoses I dealt with required 10 to 15 years of constant attention to ensure a maximal habilitation of the infant becoming a toddler, becoming a child, becoming an adolescent. I molded those youngsters as best I could into the best they could be -- my interest was very proprietary. I was aware of the situation and tried to maintain a reasonable balance. How much more difficult for the reluctant physician!

Because our society is so mobile, new patients are sometimes referred mid-stream; in these instances, I found it hard to feel the same degree of interest in an inherited case as I had in one I had cared for since birth. It must have been the same for my patients whom I transferred elsewhere.

My point is -- if these feelings exist within pediatrics -- how much more stressful might this be when transferring to adult care.

Even today, former patients still beat their way through the bureaucracy to ask one to intervene when barriers have become insurmountable. Frequently, these barriers stem from faulty communication or unreasonable attitudes.

There are other points to be made and addressed:

- Existing knowledge gaps must be filled concerning techniques, community resources, experience of others, and achievable goals.
- The range of care delivery models must be assessed and documented.
- Methods of coordination with other services must be explored.
- The financing of care must be regarded as an immediate priority.

We are talking about labor-intensive care, increasingly expensive, and the reimbursement systems which have not caught up with these facts.

Children with special needs entering the adult system are not overly welcomed because:

- They should many times overstay their DRG norm.
- They may not be covered -- any longer -- by their parents' insurance.
- If employed -- even part time -- they may be part of the working poor -- uninsured but not destitute enough to be on welfare or even eligible for medicaid.

For the rest of this century, everything we discuss in reference to medicine, health care delivery or policy will merely be symptomatic of the overarching tension between our aspirations for health care and our resources to pay for them.

The two populations at greatest risk of medical neglect are the elderly and children. We will have to fight harder than ever for the funds to care for special needs children and young people.

It is unlikely that any administration or any Congress will address this issue on the clear merits of the situation -- in spite of the nation's affluence and prosperity. But the day will come when the business community will exert much greater pressure than at present for a more realistic method of funding health care. We must be prepared for that day so our special needs children are not shortchanged as the health care delivery system is rebuilt. We must be certain that there is adequate documentation of the essential range of health services so that implementation may take place without delay as soon as resources are made available.

These are the issues we ask you to discuss with us over the next two days -- along with any additional ones from your experience you would like to bring forth.

Let us clearly identify the problems and plan concrete efforts which each of you can pursue within your own organization. Let us then outline some efforts we can jointly pursue to knock down the barriers currently preventing our young people from living their lives to the fullest.

## **A Background Issue Brief**

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Over the past 20 years, there has been a dramatic improvement in mortality rates for many chronic "childhood" conditions due, in large part, to advances in medical and surgical care. Survival rates for disorders such as spina bifida and leukemia have increased by almost 200 percent. The average age of survival for young people with cystic fibrosis is pushing well into the twenties with one third living into their thirties. It has been estimated that, overall, some 84 percent of children with chronic conditions survive into adulthood.

Unfortunately, in many cases, the medical care system has not changed in response to its own successes. Large numbers of these "survivors" continue to receive their medical care in pediatric settings. It is not uncommon to see patients in their late twenties receiving inpatient care on pediatric wards and in children's hospitals. Others are simply lost to ongoing follow-up once they "outgrow" pediatric services, since no specialty services addressing their condition exist in the adult medical system.

This situation has a negative impact on these young people in several ways. While the pediatric caregivers who have provided speciality care throughout their childhood are typically indisputably expert in treating their special conditions, they may not have the expertise to address the medical needs of adults. Issues related to gynecology and obstetrics for young women and other disorders of adulthood which may be unrelated to the young person's special health care needs may not be addressed as well as they would be in the adult health care system. In addition, other pediatric subspecialists providing consults may also lack experience with "adult" disorders or the manifestations of a given problem in the adult population.

Another way in which receiving medical care in pediatric settings may have a negative impact on young adults is in relation to their own psychosocial development. Pediatric caregivers may have a difficult time switching from dealing with the parents as the responsible parties to dealing with the young adult. It is hard to accept that the child one has cared for is now an adult and pediatric caregivers may collude with parents in "overprotecting" the young patient. Issues such as sexuality, reproduction, vocational concerns or even the financial aspects of care decisions are often not discussed with the patient, as they would be in the adult health care sector. Even the best efforts at education in these areas by pediatric caregivers may be ineffective if the patient feels that his/her parents make the decisions about care. Remaining in pediatric care settings becomes one more factor impeding the development of adult independence in young people with special health care needs. Finally, there is a very insidious, negative message in keeping these young adults in pediatric care. It is an understandable by-product of the history of the mortality of many of these "childhood" disorders, but it is devastating. The failure to develop a capacity to care for these young adults in the adult care system suggests that we believe that they are living on "borrowed time". It gives the message that working to make the difficult transition to adulthood may not be worth the effort, because it may be a greatly shortened span of time!

Young people who do not have special health care needs seem to make the transition to adult health care with little fanfare. Why does there seem to be this bottleneck in the progression for youth with special health care needs? A number of factors seem to play a role in the problem. These include: attitudinal barriers (on the part of pediatric and adult caregivers, families and patients) knowledge gaps; care delivery models typical in adult health care; financing of adult health care services and coordination of health care services with other needed services. Each issue must be addressed in order to insure that youth with special health care needs can grow up and find appropriate medical care.

### **Attitudinal Issues**

Those who have attempted to facilitate the transition of young adults to the adult health care system have quickly discovered that the issue arouses very strong feelings. Parents are often quite reluctant to leave the pediatric caregivers who they often view as having kept their child alive, in order to seek care in untested waters. These feelings are particularly acute when their child's disorder is one that is not familiar to the adult caregivers. Parents may have close personal ties with the pediatric caregivers forged during moments of crisis and shared worry. The clinic and hospital staff are often a major part of the family's support system. Parents who experience the move to adult health care settings have a hard time adjusting to the focus on the young adult as the responsible party. They complain of feeling shut out and ignored when the adult caregivers consult with them as a courtesy with the permission of the young adult patient. Thus parental resistance to the move can be quite strong. Many young people share their parents' fears about the change as well, although most express very positive feelings about being "treated as an adult."

The caregivers' attitudes also make the transition problematic. Pediatric caregivers also have strong ties to the families and the patients--it is very hard to see them leave. They have a difficult time really believing that the child they may have cared for from birth is truly an adult (or should at least be treated as one.) They feel that no one in the adult system has the expertise to deal with the patients' medical problems and, more importantly, that adult caregivers are cold and uninterested in these patients' many psychosocial needs. On the other side of the care system, adult care providers may feel that these patients are immature and their families too involved and demanding. If they do not have experience with a young person's special condition, the caregivers may feel defensive or threatened about seeking consultation or supervision from pediatric caregivers who specialize in the treatment of the disorder. Certainly there is no incentive to pursue the treatment of a group of patients if one does not have the knowledge and experience to do so.

These attitudes must be addressed in any efforts to change the system of care. When the problems and setbacks that attend any change come along, it is too easy for any or all of the parties involved to feel that "it isn't worth the trouble" or to be too quick to see any problem as proof that their worst fears have been realized.

### **Knowledge Gaps**

One very real barrier to a smooth transition to adult health care for youth with special health care needs is the lack of knowledge and expertise in the adult care system to deal with their special problems. Some of the disorders involved have been historically thought of as "pediatric conditions", many of which are cared for in special centers or units. As a result, physicians and other caregivers in the adult system may have little knowledge and no experience caring for these disorders. Some form of training and expanding knowledge is needed to make the transition from pediatric settings, where the staff have had years of experience with a particular disorder, to the adult settings.

While these young adults with special health care needs should be treated as adults, many have had delays in both the physical and psychosocial aspects of adolescence. Thus many in their twenties are more like mid-adolescents in their development. Their families are also often still unresolved about letting go and making the move to becoming the parents of an adult child. A large proportion of adult specialists may not have had training in the issues of adolescent development and may be perplexed and frustrated in caring for this population. This lack of knowledge can easily undermine the success of the transition.

### **Care Delivery Models**

Over the years, the pediatric system of care has recognized that interdisciplinary team care is the most effective model for serving children with special health care needs and their families. Many of the disorders treated need the input of multiple professionals, all of whom must have a familiarity with the special aspects of the care of a particular condition. While the interdisciplinary team approach to care has made an appearance in the adult health care system (e.g. cardiac care clinics, diabetes centers, etc.), it is not the model available in most specialty departments. Many physicians in the adult care system are unfamiliar with or even

uncomfortable with this model of care. It is important that in seeking to find medical services in the adult sector, young people with special health care needs do not have to give up the model of care that is critical for appropriate treatment of their chronic health conditions.

### **Financing Care**

The financing of care for young adults with special health care needs is a problem that has an overriding importance for the issue of growing up and finding medical care. There are issues for caregivers, institutions and consumers. Caregivers may find that caring for these young people is more time consuming than usual, yet reimbursement systems may not adequately recognize this factor. In addition, team care is very costly and again, reimbursement systems may not provide adequately for the many kinds of services needed. Inpatient hospital care in adult institutions, where DRG's have been applied, may be problematic. Because of the complex nature of their medical problems, these young patients may be seen as a drain on resources, when DRG's do not recognize their real need for prolonged hospital stays. Even in states where there are public programs to help pay for care of specific conditions after the age of twenty-one, the agencies administering them are child oriented and may relate only to pediatric institutions or caregivers. Finally, a very serious issue is the fact that these young people typically find themselves without any health insurance coverage. Once they reach the age of twenty-two or leave home and school, they are no longer covered under their parents' policies. If they are gainfully employed, they may not qualify for public sources of medical coverage. Often they also find that they cannot secure full time employment, because they are a risk that employers do not want to insure. Thus, incentives to become productive, independent adults may be undermined in order to deal with financing health care needs.

### **Coordination With Other Services**

Young people with special health care needs often have many other associated needs. They may need a variety of special therapies, special equipment, extra training to help with vocational fulfillment, special diets, and special accommodations in the environment. During childhood, the educational system and the medical system may coordinate many of the services for the child and family. The adult care system, not having dealt with these particular needs, may lack knowledge of resources and ties to the resources needed. Development of these ties within the adult care system will be needed to insure appropriate care for these young adults. On the positive side, the adult caregivers are much more familiar with many types of services that will aid in the growing independence of these young people in the areas such as vocational development.

This paper is certainly not meant to be an exhaustive discussion of the issues related to transition to adult health care for youth with special health care needs. These are, however, the key issues that will need serious consideration throughout the system. Clearly, members of the pediatric and adult health care systems, families and young adult consumers must all become actively engaged in the process if positive change is to be effected. Many of the statements are generalizations and there are specific instances when youth with special health care needs can access appropriate adult health care services. There is, however, much work to be done.

## Section I

### Overview and Scope of Problem

In order to present the concept of adolescent transition from more than one perspective, papers were requested from professionals who were known to have a special viewpoint based on their own life experience or special interest.

We have an introduction through the highly personal experience of a young woman who felt deeply the emotional discomfort of leaving the protective warmth of Pediatrics for the cooler clinical atmosphere of an adult service. However, unlike others, she was able to make a personal adjustment, and to survive with distinction.

A pediatrician speaks for professional health staff when they are faced with implementation of a transition program. The increased life expectancy of children who have cystic fibrosis made it necessary to develop a bridging program between a Children's Hospital and an adult pulmonary unit. From this paper, we learn about the importance of preparing young people for this transfer and to choose the optimal time for the event. The benefits of an interdisciplinary care team are described. The difficulties experienced in developing a strong link between these two programs are not minimized, and we have a realistic picture of the reluctance and rewards associated with the growth of such cooperation. We see these events occurring through the eyes of the responsible health care providers.

A health care financing expert addresses the universal burden carried by disabled adolescents and their families. She has given a succinct account of the financial dilemma faced by nearly all individuals in this category when eligibility for medical insurance benefits is curtailed by age, and they fail to qualify for coverage through state or private schemes. The points are made through discussion of an imaginary young adult - and specifying the available options and alternatives available for obtaining payment for essential medical care.

The paper on training emphasizes the importance of an appropriate orientation for professional staff, patients, and their families when improvement of the transition process becomes a priority. Staff in both pediatrics and adult health services should work together and share relevant information; this should be a continuous process before and after transition. The technical aspects of managing rare medical conditions with which the adult physician may be unfamiliar, must be included in the curriculum. Attitudes and communication skills are central to the successful shaping of new relationships between staff and young patients.

## **Learning to be an Adult Patient: When the Rules Change**

**Margaret Stineman, M.D.**

My own medical treatments, most of which were surgical, began at age three and continued into my adult years. I do not want to talk a great deal about the specifics of my medical condition or surgery. Briefly, I had procedures on my eyes, my musculoskeletal system, and my internal organs.

When I was a child, I would always bring my guitar to the hospital. I named the guitar. Its name was "Friend." I was in the hospital often, so the staff came to welcome me and "Friend." I would make up songs - sing for the other children, for the nursing staff, the doctors, and the orderlies. Everybody was interested in my guitar and my musical gifts. Sometimes the nurses from the adult wards would borrow me to cheer up their patients. The older folk would marvel at my "courage," and feel inspired by the songs saying things like "Poor little thing, in spite of all her problems she can smile." I treasured these times, since by lifting the spirits of those around me, I forgot the hurt. One man who, looking back, must have had laryngeal cancer sent me a book of Emily Dickenson's poetry. In the cover was inscribed "Dear little Margaret, I can not use my voice anymore. Your songs are my words."

The guitar was a way that I could feel comfortable and accepted within an environment that inflicted physical pain on me, and left me frightened and set apart from my peers. It was a way of reaching out to other people. In letting me play my guitar the pediatricians, the surgeons, the nurses, and all the people in the hospital let me show them that I was a human being who just happened to be physically different. After a spinal fusion, I learned to play the guitar lying flat on the bed without moving. It would draw people to me. I would not feel so alone. So different.

I made my own transition from pediatric into adult health care on schedule quite abruptly when I was 16. I can recall sitting on starched white sheets in my semi-private room, taking Friend out of its case and quietly beginning to pluck out a melody. No one marvelled at my courage. My songs inspired no one. No one saw my gifts. Nobody was drawn to listen. In fact, I suddenly blushed realizing that playing my guitar within the sterile walls of this hospital room was disquieting to the nurses, the doctors, and the patients. In fact, it was down right infantile. I sent my guitar home with my parents. I had to face the fact that appealing crippled children on posters grow up to be uninspiring physically deformed adults. The adult medical milieu was no nonsense. It was interested in one thing - the expedient treatment of disease - the cutting - the curing. It appreciated the privacy of the individual at the expense of personal sharing and expression. The doctors and the nurses had little time or inclination to know the patient. In my own medical internship, I would need to confront this tragic fact made vivid by my past experiences. When suffering from post call sleep deprivation, or when struggling to save lives one can not always see or hear the patient. So to survive, I was forced to adopt the methods of those who had cared for me, even though I knew this approach was imperfect. The guitar for me as a child was a calling out of who I was. As an adult I had to close myself, and just become a patient. The care of disabled children is holistic and team driven. The young child is seen as developing within the context of family. Disabilities are noted, but more importantly abilities are seen and encouraged. An attempt is made to view illness within the context of a life. I found this less to be the case as an adult. There is a supportive aspect of pediatric care which is lost in the transition into adult care. The care of the adult is disease oriented, less holistically supportive. This was one of the most difficult aspects of my transition into adult care. One minute I was in a nurturing environment that attempted to see me as an individual that happened to be physically unusual. The next moment, I was in a medical milieu that did not care to look beyond my physiological impairments.

As a child the many procedures, diagnostic tests, and surgeries were done on me as a passive participant. The doctors, the nurses, the therapists had some special knowledge. Children are not good at tolerating pain. The physicians seemed to feel that reasoning about the necessity of drawing blood is going to fall on deaf ears. In fact, I put up gracefully with the various procedures I

had in my early years because I felt there was no alternative. The doctors knew everything. I had no right to question. It all ran by magic law. Each time, I was rolled into the OR I thought I would roll out normal. If I didn't it just meant I needed more surgery. Decisions were made by my doctors, my parents, not by me.

At age 18, I was absolutely dumbfounded when a resident turned up in my hospital room with a consent form for surgery. This doctor was telling me there were risks that I could die, and that I personally would have to accept this possibility. I saw death about me in the hospital as a child but had not connected it to myself. Where were my magical pediatric illusions? The doctors in pediatrics were so magical. They could cut and fix my body. They had never told me I could die. Now I sat in a foreign land. A different hospital. A different health care system. I was supposed to become part of the decision making process. I could take control, but I did not know how. Did I even want to take control? How could I ask questions? How could I make a decision about a medical procedure or the need for surgery? For 16 years the decisions were made for me. Although, at 18, I signed the consent form, I neither read nor comprehended it. I signed it, not because I wanted the surgery, but because I had always done what had been asked of me. The results of the surgery would direct the remaining years of my life.

As a disabled child I was an infant. As an adolescent I was a child. In my adult years, I would finally pass through adolescence. Prolonged infancy encouraged dependency. This made the acceptance of personal responsibility difficult. As an adult aged patient I felt cast into a foreign sea. My boat had oars, but I did not know how to use them. In broad terms the adult seeks care, the child receives care. The developmentally immature adult in the adult system of care is a victim since he or she is assumed to be autonomous.

Please realize many of the children we will be thinking about today have far greater physical problems than I do. And few have the remarkable family support I have. Many might feel differently about their transitions into adult care. Others may never even make it, forever remaining children in adult bodies, and still others may make it but in the confusion become lost to the health care system entirely. I was lucky. I am an example of what should, and can be, but what rarely is. Only with my present vision can I make sense of my past experiences. There were four primary differences in the two systems of care that led to difficulty in my transition. First, was the change in both type and level of support. Second, was the change in the decision making and consent process. Third was a marked reduction in the acceptance of family participation. Fourth, was a reduced tolerance and sensitivity to the psychosocial issues of disability.

We have a magnificent system of health care in this country. The fact that I can stand here before you today is attributable to that fact. Now I am proud to take my place in it as a physician. Through our medical advances, we are giving life to children who in the past died. These children are now entering adult care. They bring new problems to a system that is unfamiliar with childhood disabilities and developmental problems. I believe that our ability to care for the person has fallen short of our capacity to care for the disease. Neither the pediatric nor adult care specialties are at fault. Each needs to adapt, and form collaborative bridges to and from the other. The briefings I read in preparation for this conference are an excellent beginning. They imply a sharing of expertise, and a coordinated transition plan. It was primarily the stark contrast between the two systems of care and abrupt transition that seemed problematic.

**Growing Up and Getting Medical Care:  
Youth With Special Health Care Needs  
Obstacles to Transition from Pediatric to Adult  
Health Care Systems**

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The result of medical progress has been an increased survival rate for children with chronic diseases. The prevalence and median survival of diseases characteristically thought of as "childhood illnesses" in the past has increased steadily over the years. A significant number of patients with conditions such as cystic fibrosis, diabetes, spina bifida, end stage renal disease, operated congenital heart disease, etc., live nowadays well beyond the second decade of life. These patients represent a significant segment of the entire population of patients with chronic disease, and, as they grow older, they create an increasing demand for specialized care (Table 1). For instance, the survival for patients with cystic fibrosis has gone from a median of about one year in the 1950's to 27 years of age in the late 1980's. Over 1/3 of the population of patients with cystic fibrosis currently registered at accredited centers in the United States is over the age of 18 years.

Many adolescents affected by chronic disease must be prepared eventually to confront life as adults. Childhood and early adolescence in unaffected children are characterized by strong parental involvement and little shared decision making. Dependency is a norm concerning insurance, economics, transportation and emotional well being. The individual's main occupations are schooling and recreational activities. Family physicians or pediatricians care for these children until their emotional or physical needs may demand the care to be given by an adult specialist. Adult living is characterized by independent living, self reliance, and meaningful relationships. The growth and development of the chronically ill child and adolescent should approach, as much as possible, that of the unaffected individual. The normal pattern of development includes the transfer of care from pediatric to adult caregivers.

The process whereby this transfer takes place should be smooth. There needs to be a "transition" period during which the changes take place.

Why transition? The goal of transition programs is to achieve for each chronically ill individual a normalization of social and emotional development by providing the ideal environments in which independence and self reliance flourish. A successful program should result in improved compliance with therapy and effective planning of long range life needs. In the context of this scenario, it is our belief that transition from pediatric to adult health care systems is desirable as a reflection of the normalization of the individual's social development. The benefits of transition may be listed as follows:

- Normalization of development,
- Promotion of independent behavior,
- Promotion of self reliance,
- Improvement of compliance with therapy,
- Provision of an appropriate environment,
- Planning long-range life goals.

**Table 1**  
**Estimated Prevalance and Maximum Prevalence Estimates for Eleven Childhood Diseases**  
**Ages 0-20, United States, 1980**

Disease	Estimated proportion surviving to age 20 (percent)	1980 prevalence estimate per 1,000	Estimated maximum prevalence assuming 100% survival to age 20, constant incidence and age of onset
Asthma (moderate and severe)	98	10.00	10.20
Congenital heart disease	65	7.00	9.33
Diabetes mellitus	95	1.80	1.89
Cleft lip/palate	92	1.50	1.62
Spina bifida	50	.40	.67
Sickle cell anemia	90	.28	.29
Cystic fibrosis	60	.20	.26
Hemophilia	90	.15	.16
Acute lymphocytic leukemia	40	.11	.22
Chronic renal failure	25	.08	.19
Muscular dystrophy	25	.06	.14
Estimated total (assuming no overlap)		21.58	24.97

**Source:** Gortmaker and Sappenfield, 1984

Where do the obstacles to this transition process lie in the field of health care? Patients will be unable to have their care transferred effectively from a pediatric to an adult health caregiver if their behavior is extremely dependent or immature, or if the degree or instability of their illness is such that transition is unadvisable or risky. Mental retardation or psychopathology has proven to be a particularly difficult hurdle to overcome in our experience, as is the lack of good support systems, i.e., an encouraging family or partner. Patients who have a basic mistrust in their caregivers will view attempts to transfer care as abandonment or lack of interest, and finally, those who do not comply with therapeutic regimens tend to be reluctant to change as well and uncooperative with innovation.

The Family. For successful transition to occur, it is very important to include the family in the equation. To a great extent, transition is a family affair and its success depends on the cooperation of those people who constitute the support systems for the individual. Transition truly starts at birth and should continue throughout adolescence into adulthood. Parents should try to endow their children with the necessary tools to achieve independence and self reliance. Emotional dependency on the part of the parents, excessive need for control of the child's behavior and activities, and parental psychopathology mitigates against successful transition. The perception of the disease process as lethal at an early age (even when this is not necessarily accurate) or the perception of the patient as unduly healthy or unduly sick, will hamper efforts to achieve transfer of care effectively. Mistrust in caregivers is also a serious obstacle.

The Pediatric Caregiver. This area is one of the most important and essential to successful transition. Many pediatricians who have invested their careers in the care of these patients, see with some apprehension their transfer to a new source of services. They may see it as a serious blow to their economic or programmatic base, their ability to support their health teams and their research and educational activities. Some will allege a "poor return on the investment" of having to help train adult specialists unfamiliar with the disease. They may have no confidence in the ability of their adult colleagues' care for these patients. Some may feel that they have the skills necessary to deal with all aspects of care of a particular disease regardless of the age of the individual. Others may hide a subconscious feeling that the patients indeed have a short life span and change of caregiver is traumatic and unnecessary, or that the adult patients can be comfortably and appropriately cared for in pediatric institutions by pediatric health care teams. The overriding concerns seem to be the economics of losing patient base and the strong emotional bonds between pediatric care givers and patients and their families.

The receiving end: the adult caregiver. The adult health care system has not been ready, by and large, to care for these patients. Lack of knowledge of specific disease entities, heightened perceptions of the demands of care, and economic concerns stand in the way of a more receptive attitude. Health care administrators worry about the potential negative impact of undersupported chronic disease programs.

Adult caregivers have insufficient understanding of the nature of congenital diseases and may have a rather "catastrophic" view of their clinical course. It is of interest, however, that the transfer of care from pediatric to adult systems occurs naturally for certain conditions such as diabetes or end-stage renal disease. This fact is possibly related to the degree of expertise already present in these areas in Internal Medicine. This is not, in general, the case with conditions such as congenital heart disease, cystic fibrosis or spina bifida.

The process of transfer from pediatric to adult health care systems is by no means easy and requires effort by all parties. The initiative and leadership must originate, in my view, from the pediatric caregivers and be strongly supported by interested caregivers in the adult health care community. Parallel systems at the tertiary care level as well as in the community need to be structured with the participation of a variety of professionals. Some of the necessary conditions for transition from Pediatric to Adult care are:

- A Pediatric team leader,
- An Adult team leader,
- Ongoing collaboration and sharing of responsibility,
- Patient and family preparation (coordination of needs with attitudes),
- Team building and communication,

- Administrative and economic planning,
- Interagency collaboration.

For the adult caregiver unfamiliar with the care of chronically ill children and adolescents, but who is interested in helping establish the transitional bridge, this process presents opportunities for professional fulfillment, prestige, research opportunities, career advancement, use of innovative approaches to health care, emotional rewards, and in most cases adequate reimbursement.

It would be naive to expect this process to be simple. On the contrary, it is fraught with difficulties. Emotional and financial issues are closely intertwined and may easily weaken efforts to meet the goals previously described, if not dealt with promptly. Economic support for multidisciplinary care, widespread education and support of health care activities is still insufficient and more is needed. Insurance coverage for chronically ill individuals attempting to leave the parental home is difficult to get and presents a grave concern. Some states have expanded through their Crippled Children's programs or line items in state budgets to these specific adult programs. The budgets and numbers of these programs are insufficient at this time to cover all the needs of these individuals.

The future brings new challenges and issues of concern. These issues must be faced not only by health caregivers but by the community as a whole, including government, private industry and consumers. Issues for the future include the following:

- Methods to increase the number of transition programs,
- Ways to achieve interagency collaboration,
- Definition of the scope of "over 21 state programs",
- Medical insurance for the young disabled adult,
- Home and community based care,
- Role of state Crippled Childrens programs.

Our program at Temple University School of Medicine in Philadelphia, Pennsylvania will be described by Dr. Stanley Fiel later in this meeting. Our experience and that of others indicates that transition is not an impossible task. It is our firm conviction that transition from pediatric to adult health care systems for chronically ill youth is desirable, feasible, and rewarding.

## **Adolescents and Young Adults with Special Health Care Needs: The Challenge for Financing**

**Peggy McManus**

### **Introduction**

Obtaining major medical health insurance -- either private coverage or Medicaid -- for young adults with special health care needs is a very serious problem. It makes the insurance problems of pregnant women, adolescents and chronically ill children look minor.

Today, more than 20% of disabled young adults, ages 19-24, are without any form of health insurance protection at all. Thousands more are insured but without adequate coverage for the services they require. I don't know how many of you have actually attempted to find coverage for someone who is uninsured and has a pre-existing condition. Let me assure you it is not easy. And, unfortunately, in many instances it is impossible, unless the young adult moves to another state, or lands a job with insurance benefits, or becomes more disabled, or pregnant. Still, I believe there are many real financing options that we can take better advantage of now in our own communities and at the federal and state levels.

I am honored to be here to present new findings from our study on adolescent health insurance coverage funded by the Bureau of Maternal and Child health. Briefly, a year and a half ago, Paul Newacheck of the Institute of Health Policy Studies at UCSF, Harriette Fox and I received a three year grant from the Bureau of MCH to analyze the health insurance needs and options for adolescents and young adults.

I will begin my presentation with a few facts on adolescents and young adults who have special health care needs. Next, I will discuss the hypothetical case of Susan, aged 18, with juvenile diabetes -- not unlike the case of John in our agenda materials -- and play out a probable scenario if she were privately insured, publicly insured or uninsured. I will use this case example to show what short and long-term financing improvements might be attempted.

Although there is much to discuss in financing, I am going to limit my presentation to ways in which Susan and John may retain insurance coverage after they lose their "dependent umbrella" under their parents' plans, and also how to get the uninsured Susans and Johns of this world some insurance benefits. I will not be addressing ways to improve benefit plans or reimbursement -- two very critical issues.

The major themes I would like to leave you with are these:

- We have a serious insurance crisis for young adults with special health care needs and one that cannot be simply solved with what is available today. The major problems are that their access to private or public health insurance plans is very limited - in fact, many refer to this group as medically uninsurable; their premium costs and other cost-sharing requirements are unaffordable considering a typical young adult's income; and finally, once insured, their plans are often woefully inadequate. Consequently, I believe significant reforms in both the private and public sectors will be required to have a significant effect on these problems.
- The second theme is that the sooner disabled adolescents and young adults and their families are counseled about their financial options, the better the results will be. The best time is when these young persons are ages 17 or 18, not 20 or 21.

### **Facts**

Who are the disabled adolescents and young adults about whom I will speak? According to the 1984 National Health Interview Survey, they are the 6% of all noninstitutionalized adolescents or nearly 2 million 10-18 years olds (1), and 5% of all young adults or almost 1 1/2 million 19-24 year olds (2) who suffer from chronic conditions that limit their ability to engage in school, extracurricular activities or work. In general, I am speaking about a relatively small population

Table I

**LEADING CAUSES OF DISABILITY AMONG ADOLESCENTS 10 TO 18 YEARS:  
U.S. 1984**

<b>Main Cause of Disability</b>	<b>Estimated Prevalence (in thousands)</b>
1. Mental Disorders	634
2. Diseases of the Respiratory System	406
3. Disease of the Musculoskeletal System and Connective Tissue	295
4. Diseases of the Nervous System	115
5. Diseases of the Ear and Mastoid Process	80

**SOURCE:** National Health Interview Survey: original tabulations from public use tapes. In: Newacheck, Paul: Adolescents with special health care needs: prevalence, severity and access to health services. Pediatrics. Forthcoming.

Table 2

**HEALTH CARE COVERAGE CHARACTERISTICS  
ACCORDING TO DISABILITY STATUS  
FOR ADOLESCENTS (10-18 YEARS) AND YOUNG ADULTS (19-24 YEARS):  
U.S., 1984**

<b>Health Care Coverage Status</b>	<b>Adolescents with Disabilities</b>	<b>Young Adults with Disabilities</b>	<b>Adolescents without Disabilities</b>	<b>Young Adults without Disabilities</b>
<b>Total with Coverage</b>	86%	79%	86%	73%
<b>Private Coverage</b>	68%	57%	76%	67%
<b>Public Coverage</b>	22%	28%	11%	7%
<b>Total with no Coverage</b>	14%	21%	14%	27%

**SOURCE:** National Health Interview Survey: original tabulations from public use tapes. In: Newacheck, P. and McManus, M. Health insurance status of adolescents in the United States. Pediatrics. Forthcoming.

with significant needs for major medical insurance protection.

The leading causes of disability among adolescents, ages 10-18, according to Paul Newacheck (3) are mental disorders, diseases of the respiratory system, diseases of the musculoskeletal system and connective tissue, diseases of the nervous system, and diseases of the ear and mastoid process (see Table 1). Taken together, these five chronic conditions represented 3/4ths of all disability among noninstitutionalized adolescents in 1984.

Preliminary data on disabled young adults from the 1984 National Health Interview Survey show that diseases of the musculoskeletal system and connective tissue are the leading cause of disability followed by mental disorders, diseases of the respiratory system, nervous system, ear and mastoid process.

What is the insurance status of adolescents and young adults with these chronic disabling conditions? You can see from Table 2 that 14% of disabled adolescents or 270 thousand adolescents and 21% of disabled young adults or 300 thousand young adults are uninsured. Taken together, this represents a little more than 1/2 million young persons without any form of health insurance protection.

Let us look more closely at the population of disabled young adults, on whom we are concentrating today. How do they compare to disabled adolescents? According to Table 2, young adults are 50% more likely to be uninsured. Only 57% are privately insured - 16% fewer than disabled adolescents, and 28% are publicly insured - 27% more than disabled adolescents.

How do disabled young adults compare to nondisabled young adults? They are four times as likely to be publicly insured as their nondisabled counterparts, as shown in Table 2. Notwithstanding, over half of disabled young adults are still privately insured.

What difference does health insurance make for disabled young adults' access to primary care? According to Paul Newacheck (1): "Disabled adolescents without health insurance were almost three times as likely to have delayed seeing a doctor for 2 or more years compared to disabled children with insurance coverage."

### **Case Study**

Turning from national facts to a real life case example with which we can all identify; Susan is aged 18 and has juvenile diabetes. Looking at Susan in some different financing scenarios, we can review her benefits and predict how financial counseling might be helpful. The choice for Susan who is aged 18, not John who is 21, is intentional because the sooner the young adult and his or her family are counseled, the better the chance of reasonable insurance coverage. Susan is privately insured by her father's group health insurance plan and she will be completing school in June. Her health insurance options will depend upon whether she stays in school, works, gets married, lives at home, or lives on her own.

1. First and foremost: Susan's parents should find out at what age she will lose coverage under her father's plan. In most major medical plans, the magic age is 18 unless the individual is regularly attending school. Susan's parents should also be informed that many employers are even lowering the age of qualified dependents regularly attending school -- down from 22 or 23 to 18 or 19.
2. Whether or not Susan goes on to college, her parents have at least one option for keeping her on their plan. It is called the COBRA continuation policy. If Susan's father works for a company with more than 20 employees, he needs to notify his employer within 60 days after Susan's 18th birthday that she will no longer qualify as a dependent and that he wants to purchase the company's group plan for her. Of course, Susan's parents or Susan will have to pay the full cost of the plan -- which might come to about \$2,000 per year. This COBRA continuation policy is available for three years. While expensive, no pre-existing condition exclusions can be used and they must offer the same plan as previously available. Moreover such a group plan would be less expensive than a comparable non-group plan.
3. Another option for continuation is as follows: Again, before Susan turns 18, her parents should call their state health insurance commissioner's office or local advocacy group to find out if they reside in a state that has mandated a law which requires that handicapped and financially dependent young adults can remain on their parent's policy. According

to a recent Blue Cross survey, 34 states have such a mandate. Under this rule, Susan's parents must notify their employer within 31 days of her loss of dependent coverage or their application will be unsuccessful. This mandate does not apply to employers who self insure, and over 50% are in this category. As you can see, the age of 18 is a very important time for financial counseling for adolescents with special health care needs.

4. If Susan is going to college, even on a part-time basis, she should be encouraged to purchase a student health insurance plan if it is offered, and if she qualifies. In our 1988 college health insurance survey, almost half of all plans had a pre-existing condition exclusion, and another third imposed a waiting period for pre-existing conditions. The rules for pre-existing conditions vary. Typically, coverage for treatment of the pre-existing condition is excluded but other ongoing health needs are covered. In addition, many plans have a pre-existing condition waiting period for various lengths of time, commonly 1 year, after which time, coverage will be available. In other words, Susan may need to purchase the insurance for one year so that she can have subsequent coverage. Note: Student health insurance plans are distinct from the student health center services available at most colleges. Student insurance premiums are very inexpensive - about \$250 per year in 1988 (4). As might be anticipated, student health insurance plans vary dramatically in their quality, with state universities and larger colleges offering better plans in general.
5. If Susan is not going to school, she should be encouraged, if at all possible to seek employment on a full-time basis in a medium to large firm. Otherwise, she may be totally incapable of gaining employment based insurance.
6. If Susan cannot continue with her parent's plan, cannot get student health insurance, cannot get employer-sponsored health insurance, then she is in serious difficulty... This, of course, is exactly where our financing system disintegrates for Susan and all the other young adults with special needs in this country. In this instance, she should be advised to contact Blue Cross for information about their open enrollment period, and also contact other large federally qualified HMOs for information about any open enrollment period. This happens only rarely -at best once a year- and it is not advertised, for obvious reasons.
7. At this point, Susan and her family must begin to develop new investigative skills. Does the state offer a high risk pool? Presumably she would qualify if she can show proof of being rejected from insurance twice. Does the local advocacy group have any other suggestions?
8. As you can see, we have met a very serious private insurance roadblock.

**Let us now put Susan in a different family, one in which she is covered under her mother's Medicaid plan.**

1. If Susan does not go onto college or vocational training she will automatically be dropped from Medicaid as a dependent at the end of her 18th birthday, unless:
  - the state she lives in adopted the Medicaid option to cover adolescents to ages 19, 20, or 21.
2. Even if Susan goes onto college, she will automatically be dropped at age 19 under Medicaid, unless again:
  - the state she lives in adopted the option to cover adolescents to ages 20 or 21.
3. If Susan does not go onto college and works and stays at home or lives on her own, she can attempt to qualify for AFDC or SSI or general assistance under Medicaid. Unless she is pregnant or disabled enough to meet the stringent SSI requirements though, she will not qualify for Medicaid.
4. As you can see, we have met a very serious public insurance roadblock.

**Finally, let us put Susan in another family who is uninsured.**

1. Susan and her family can attempt to qualify for Title V. However, as you know, the financial and diagnostic eligibility criteria are limited. She can also contact her state health department to see if there are any indigent care programs for which she might qualify.
2. In the end, Susan must rely on the availability and capacity of publicly funded health

3. services and free care from doctors and hospitals and other community agencies.  
As you can see, we have met a very serious uninsured roadblock.

### **Strategies:**

To address this nettlesome issue of financing strategies at any depth would take an entire conference but briefly, there is no question that we must start counseling disabled young adults and their families no later than age 18 or we all will suffer the consequences.

See Table 3 on insurance strategies. On the private sector side, we must take greater advantage of continuation policies. In addition, it is important to develop high risk pools in every state for the medically uninsurable, as suggested by Harriette Fox (5). Beyond that basic floor, it is evident that some very significant reforms are needed. Suffice it to say we need to have at least one major medical insurance plan that is available to young adults with special health care needs. To assure that such a product is affordable, we can encourage more premium subsidy programs.

In the public sector, our challenges are just as great. Unless we can expand Medicaid to include more than those who currently qualify for AFDC and SSI, we will continue to have a public financing system that does not serve the needs of disabled young adults, particularly those who are single and living at home. As shown under Table 3, I have listed several possibilities for reform:

- Increasing financial eligibility
- Increasing optional groups
- Mandating for the medically needy
- Targeting general assistance funds
- Expanding SSI

**TABLE 3**  
**FINANCING STRATEGIES FOR DISABLED YOUNG ADULTS**

#### **Private Sector**

1. Encourage greater use of continuation and conversion policies.
  - COBRA: all employers with more than 20 employees
  - State mandate for financially dependent individuals who are mentally or physically handicapped (in 34 states)
2. Offer high risk pools in every state (available in 15 states).
3. Offer premium subsidy programs. (Model: Caring Program sponsored by Blue Cross in Western Pennsylvania)

#### **Public Sector**

4. Expand Medicaid eligibility:
  - \* by increasing the financial eligibility standards,
  - \* by covering additional optional groups (e.g., all children under 21 living in poverty)
  - \* by adopting medically needy coverage in the 14 states without it,
  - \* by targeting general assistance funds for disabled young adults who do not qualify for SSI or AFDC
  - \* by revising SSI disability and financial eligibility criteria (e.g., by eliminating the 209B option, improving the disability listings, amending the resource requirements)
5. Subsidize the purchase of Medicaid for the poor, near poor, small businesses and the uninsurable. (Model: Arizona).
6. Increase support for Title V services to include young adults up to age 25.

As with the premium subsidy programs described under the private sector, it would be most beneficial to allow near-poor families, and families and young adults with high medical expenditures the option of "buying into" Medicaid. Finally, in conjunction with other traditional

insurance reforms, it may also be wise to consider expanding Title V's mandate and funding to include young adults with special needs.

Both Susan and John need an insurance plan. Today over 20% of our Susan's and John's do not have any and the likelihood that they could qualify for public or private insurance in the U.S. is minimal. This is something that must be corrected soon in order to increase their chances of a reasonable transition to adulthood.

### **References**

1. Newacheck, P. and McManus, M. Health insurance status of adolescents in the United States. Pediatrics (forthcoming Fall 1989).
2. McManus, M., Greaney, A., and Newacheck, P. Health insurance status of young adults in the United States. Pediatrics (forthcoming, Fall 1989).
3. Newacheck, P. Adolescents with special health care needs - prevalence, severity, and access to health services. Pediatrics (forthcoming, Winter 1989).
4. McManus, M., Brauer, M., Weader, R., and Newacheck, P. The adequacy of college health insurance coverage. Paper accepted by Journal of American College Health.
5. Fox, Harriette. (May, 1988). Final project report on feasibility of high-risk pools to provide health insurance protection for children with special health care needs. Washington, DC: Fox Health Consultants, Inc.

## Staff Training for Transition Hilary E.C. Millar

In order that adolescents with special needs may achieve a smooth transition from a Pediatric care setting to an Adult health facility it is essential that plans for staff training should be included in the process. This educational component could be considered in part as a re-orientation of existing skills rather than a venture into completely new territory.

From the days of the Children's Bureau, the Maternal and Child Health Program has supported new health initiatives through Title V and related legislation by promoting staff training in all the professional disciplines. The resulting benefits have had wide recognition.

Today, we are a group composed mainly of physicians who have shown concern over the graduation of disabled teens from a children's milieu to an adult health care environment, thus underlining another developmental milestone. It is expected that physicians should take the initiative for planning a logical sequence of events for the implementation of this new focus.

However, it should not be overlooked that much of the success of Pediatric programs for children with disabilities has stemmed from the interdisciplinary team approach adopted in this setting. This inclusion of all staff members has been advantageous for patients, families and staff themselves. A core curriculum shared by trainees of all disciplines provides a solid foundation, and in no way precludes study of special areas of expertise which are best addressed within the single discipline.

### Who should be trained?

The Pediatric staff both in the hospital and the community must be willing to relinquish patients with whom they have had a long and eventful association. The briefing format of Internists and other colleagues should be studied so that the history of each young person's medical condition is understood and the current management and medical regime is clear. A willingness to continue support after transition, if this should be needed, requires thinking through before acceptance of this collaborative approach. Also, the preparation of families for this change should be made well in advance of transfer.

Those physicians who will take on the care of the adolescent as an adult will also need preparation. These will include the principal Internist at the tertiary level who is responsible for the continued planning and assessment for the young person's medical condition. This training should be extended to the wide range of sub-specialists who may be called upon for special problems. The non-medical health professionals particularly nurses, social workers, psychologists, nutritionists, and therapists for speech and occupation and physical rehabilitation should be included. The staff in the Emergency Room should at least have some briefing about this group of patients who may arrive in a critical condition.

Primary care providers must be included; these physicians and others may be hospital based, working in community clinics, or active in private practice.

### What is the content of the training?

#### Knowledge

Internists are likely to be faced with rare disease entities with which they are unfamiliar, as patients with these conditions have in the past rarely emerged beyond the confines of Pediatrics. The inclusion of adolescent health in medical school curricula has been slow, and some senior staff members may not be aware of the accumulated body of knowledge relevant to all teenagers whether disabled or not.

An appropriate core curriculum might be expanded from the following headings:

- Characteristics of Adolescents - with special emphasis on those factors which affect the uptake of medical care.
- Growth and Development in the Teen Years - showing the sequence of events and the inappropriateness of chronological distinctions.
- Effect of Teenage Lifestyle - the possible effects of substance abuse, risk taking, inadequate nutrition, sexuality issues, unsatisfactory family relationships.

- **Disease Related Limitations** - particularly in relation to sports, automobile driving, alcohol use, dating, employment, genetic implications.
- **Complications of Disease Process** - onset of degenerative processes - physical, mental, and emotional changes.
- **Legal implications** for the care of minors; to include the rights of minors, informed consent, and privacy issues.
- **Financial planning**.
- **Ability to discuss what teenagers want to know** and not to be limited to traditional areas of health education.

#### **Skills and Methods**

These are directed towards the provision of comprehensive and continuous health care.

- **Preventive Services** - these should be provided in addition to the monitoring services for the principal illness or condition. This periodic screening might include the following: vision and hearing testings, dental assessment, a full physical evaluation, review of dietary habits, weight-pattern, exercise tolerance and gynecological assessment.
- **Health Education** - particularly with reference to the characteristics of the disease - as previously, parents may have been the main recipients of this information. The structure of the health care system, especially the availability of community agencies and facilities, and an overview of the sources of financial support for the young adult are important topics for the new order.
- **Counselling** - this is not necessarily limited to medical matters, as the caregiver should be available to discuss various areas of need, or to make a useful referral to a more knowledgeable resource if more appropriate.

#### **Attitudes**

Some physicians cannot tolerate their own perception of teenagers - these individuals might well be helped to examine the cause of their aversion. When young people are thought to be consistently too time consuming, challenging, unappreciative or non-compliant as patients, it is possible that the physician is still working through his/her own adolescent difficulties. On the other hand, the older physician may be experiencing problems with his own children and the patient's behavior may be an unpleasant reminder of what takes place in his own home.

Professional attitudes may be conveyed during any interaction with young patients through verbal communication or general manner. It may be necessary to discuss areas which are highly sensitive; previously these issues may have been shared with the parents alone, excluding the adolescent. It is important to listen and not to appear to control the dialogue. An assessment of a young person's powers of comprehension will help to eliminate misunderstanding, and in any case use of technical terms and jargon is best limited to a minimum. It is desirable to avoid behavior which suggests a condescending or patronizing attitude, and at the same time it is usually helpful to retain a measure of professional identity.

#### **Inclusion of Parents and Family**

Parents may reflect their long association with the health care system and feel they know a great deal about their son's or daughter's condition. Provided that the young person agrees, parents should continue to be included in discussions of new information and further decision-making. They may be paying medical bills, and providing board, lodging and tuition as well as giving highly valuable general support. Even when relationships within the family are poor or missing altogether, this bond is of central importance to the young disabled person - the family is usually the main source of emotional and economic support. Parents have lived through many crises in raising a child with a disability; these have occurred at birth, at school entrance, and at puberty in addition to the periods of stress when active surgery or other treatments were needed. Now the "child's" assumption of responsibility for his own medical care may be seen as threatening, and a development for which there has been little preparation.

#### **Methodology**

The successful implementation of a training program depends upon the answers to the following questions:

1. What is the objective of the training?
2. Has the process of transition and subsequent services been agreed and documented?
3. Who will provide the training?
4. Will there be joint sessions to include the Internists, Pediatricians, and other involved groups?
5. What is the curriculum?
6. Will there be study days, short courses or continuous in-service training?
7. Will training be conducted in their institution, community based, statewide, or at a regional level?
8. Will the training program be evaluated?

#### Conclusion

The time has come to implement the process of transition. There will be various models and approaches to meet the needs of existing programs. Training of staff should be discussed and developed early so that staff who participate in this transfer of care are fully prepared.

## **Section II**

### **Growing Up and Getting Medical Care: Youth with Special Health Care Needs**

#### **Case Study and Response**

##### **Case Study.**

To illustrate the issues related to growing up with special health care needs, this case study was prepared. It is a composite of many young people and many conditions. The medical condition is left unspecified, since the issues cut across diagnosis and symptomatology.

John is a twenty one year old male who has suffered from a chronic medical condition since he was two years old. At that time, he had an acute onset, requiring prolonged hospitalization. In the intervening years, he has needed numerous special treatments that have interfered with school attendance and the normal childhood business of playing, joining sports teams, and exploring the world. He has had several surgeries that have left large, visible scars. John has also had some mild learning problems in school and has always been viewed as impulsive and immature by his parents and teachers.

John's adolescent years have been difficult for him. While he has been relatively healthy, considering his condition, he still has been constantly reminded of his problem by regular visits to the local tertiary hospital specialty clinic. He has no primary care physician and has not since his problems began. In addition, he must take medication daily and cannot engage in vigorous contact sports. Like many young people with chronic medical conditions, John's condition and the drugs used to treat it have delayed the onset of puberty. In junior high and high school he was much smaller than the other boys and undeveloped. This resulted in suffering a lot of physical intimidation from his peers (being stuffed in his locker, etc.) embarrassment in gym class and social ostracism. Girls were also not interested in dating a "little boy." His depression, impulsivity and immaturity affected his behavior so that he was further ostracized. John particularly hated when peers noticed his scars and asked about them. Sometimes he told them he got them in a knife fight to make himself seem less vulnerable. John was actively involved in scouting, at his father's insistence. He achieved the rank of Eagle Scout in order to please his father.

His parents continued to attend his doctors appointments. His caregivers felt that he was immature and irresponsible and looked to his parents to make decisions and to ensure that he followed their recommendations. In addition, afraid that he would not take his medicine, his mother either made him take it in front of her or counted the pills left in the bottles. John never asked to have the medications refilled, but his mother kept track and went to the pharmacy. John's father felt stuck in his job, but did not change, because that would have left the family, and thus John, uninsured for preexisting conditions for a nine month period. John's mother, after years of devoting herself to his care, returned to work during his adolescence. She only worked part time, however, because he needed her help with school homework. John learned to drive and got his license, but wasn't allowed to go to many of the places his younger sister went, because his mother told him he would get lost going someplace new. This was also the reason he was not allowed to drive to his medical appointments alone.

John graduated from high school and entered a state college. He had never been away from home alone before, since in all his scouting activities his father had come along. He still looked like a thirteen or fourteen year old. John's roommate turned out to be a good looking, athletic boy who was very popular with the girls and had drinking parties in their room late into the night. John needed more sleep than most people his age and this was hard on him. John was determined to be socially accepted at college. He thus began to drink heavily and party every night. He also began smoking cigarettes and briefly experimented with drugs. He was unable to organize his work and was taking his medication sporadically. In part this was due to his disorganization; in part, to his belief that he was a special case that did not need this medicine.